Iona College

Thomas G. Bullen, CFC
Memorial Lecture Series
in
Science and Technology

2004-2005

Ms. SHARON TERRY, M.A.
President and CEO. Genetic Alliance

From Here to the Genome and Back Again: personal stories, genetics and populations

Tuesday, September 28, 2004

12 Noon

Joyce Auditorium
Free and Open to the Public

Sponsored by the Josephine Lawrence Hopkins Foundation
Sharon Terry is President and CEO of the Genetic Alliance and the founding Executive Director of PXE International, a lay advocacy group for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with pseudoxanthoma elasticum (PXE) in 1994, Sharon, a former college chaplain, and her husband, Patrick, founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and the public.

She is at the forefront of consumer participation in genetics research, services and policy and serves as an Ethical Legal and Social Implications Research Advisor of NHGRI/NIH, and a member of many of the major governmental advisory committees on medical research, including the National Institute of Arthritis Musculoskeletal and Skin Diseases Council.

Sharon is a member of the board of directors of the Biotechnology Institute and the advisory board of the Johns Hopkins Genetics and Public Policy Center funded by the Pew Charitable Trusts. She is a member of the Leadership Advisory Group for the Rare Disease Clinical Research Network Patient Advisory Consortium funded by the Office of Rare Diseases, NIH.

She has co-authored numerous papers including two papers on the discovery of the PXE gene, published back-to-back in Nature Genetics, June 2000. As a co-inventor of the gene associated with PXE (ABCC6), she has filed a patent application for the invention. She directs a 19-lab research consortium and manages 52 offices worldwide for PXE International. She recently founded the Genetic Alliance Biobank serves as president of its board. The Biobank is a cooperative biological samples and data repository that allows lay advocacy and community organizations to bank and manage samples, thereby accelerating research both within and across disease by providing access to fully protected, linked samples in a centralized collection.

Sharon feels strongly that consumers, working together and partnering with professionals and industry, can generate the energy and mechanisms necessary to realize the promise of basic research. Her work with the Genetic Alliance over the past few years has included working on international and national committees, particularly focused on genetic literacy, research protections, biosample repositories, technology translation, accessible services and youth issues. Sharon is committed to facilitating technical assistance to lay advocacy groups, so that each group benefits from the wisdom of the other.

Sharon lives with Patrick and their two children in Maryland.

From Here to the Genome and Back Again: personal stories, genetics and populations

Ms. Terry will speak about her journey into genetics, genomics and research. She will discuss how the diagnosis of her two children led her to become literate in science in a way she never imagined: discovery of the gene associated with their condition, and participation in the International HapMap Project.

The Project seeks to map haplotypes, blocks of human DNA. These maps might shed enough light on the enormous amount of data collected in the human genome project to make applications to health care possible. There is mounting evidence that certain haplotypes associate with certain groups of people. If they do, then there may be ways to know what treatments to give people for various diseases based on these haplotypes.

Ms. Terry has spent the last two years engaged in discussion with groups of people from Iona College and the surrounding communities. These groups have reflected on the fact that whenever a group of people is studied, there are concerns about how they will be treated, on the individual and group level. Ms. Terry will share some of the findings of her research.
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1989 - 2004

Dr. Arna Penzias
1978 Nobel Prize in Physics
Vice President, Bell Laboratories

Dr. Berndt Mandelbrat
IBM Fellow in Physics
Robinson Professor of Mathematics
Yale University

Dr. Jeremy Bernstein
Professor of Physics
Stevens Institute of Technology

Dr. Christian de Duve
1974 Nobel Prize in Physiology or Medicine
Andrew W. Mellon, Professor Emeritus
The Rockefeller University

Dr. James D. Watson
1962 Nobel Prize in Physiology or Medicine
Director, Cold Spring Harbor Laboratory

Prof. David P. Billington
Professor of Civil Engineering
Princeton University

Dr. William Gutche, Jr.
Chairman, American Museum, Hayden Planetarium

Dr. Arthur W. Galston
Eaton Professor of Botany Emeritus
Yale University

Dr. Sheldon Lee Glashow
1979 Nobel Prize in Physics
Higgs Professor of Physics, Mellon Professor of Science
Harvard University

Dr. Barry Commoner
Director, Center for Biology of Natural Systems and Professor Emeritus, Earth and Environmental Science
Queens College, CUNY

Dr. Gertrude Elion
1988 Nobel Prize in Physiology or Medicine
Burroughs Wellcome Co.

Dr. John M. Cowing
Director, Center for Computer Research in Music and Acoustics
Stanford University

Dr. Peter Brancato
Professor of Physics
Queens College, CUNY

Dr. Rosalyn S. Yalow
1977 Nobel Prize in Physiology or Medicine, Solomon A. Berson, Distinguished Professor-At-Large
Mount Sinai School of Medicine, Emeritus Distinguished Professor-At-Large
Albert Einstein College of Medicine

Prof. Freeman Dyson
Professor of Physics
Institute for Advanced Studies
Princeton University

Dr. Leon Cooper
1972 Nobel Prize in Physics, Thomas J. Watson, Sr., Professor of Science
Director, Center for Neural Science
Brown University

Dr. L. J. Zadeh
Professor Emeritus of Computer Science
University of California at Berkeley

Dr. Sidney Altman
1989 Nobel Prize in Chemistry
Sterling Professor of Biology
Yale University

Dr. John Paulus
Professor of Mathematics
Presidential Scholar
Temple University

Dr. Henry Heitnich
Director
Heitnich Institute

Dr. Mervin Schwartz
1988 Nobel Prize in Physics
Professor of Physics Columbia University
Associate Director, Accelerator Lab, Brookhaven

Dr. Nilsus Bloermogen
1981 Nobel Prize in Physics
Professor Emeritus of Physics
Harvard University

Dr. John G. Trzadal
Distinguished Teaching Professor of Engineering
SUNY at Stony Brook

Dr. Frederick T. Zugibe
Chief Medical Examiner
Rockland County, New York

Dr. Ronald Hoffmann
1981 Nobel Prize in Chemistry
John A. Newman Professor of Physical Science
Cornell University

Dr. Henry Petroski
Alexander S. Vedrin Professor of Civil Engineering
Professor of History: Chairman, Department of Environmental and Civil Engineering
Duke University

Col. Richard Sato, MD FACS
Clinical Associate Professor of Surgery, Walter Reed Army Medical Center, Researcher at US Army Medical Research and Material Command and ARPA

Dr. Thomas Elsner
Jacob Gould Schurman Professor of Chemical Ecology
Cornell University

Dr. Mary Virginia Orme, O.S.U.
Professor of Chemistry, 1984 Catalyst Award, 1989
CASE New York State Professor of the Year
College of New Rochelle

Dr. Bruce N. Ames
Professor of Biochemistry and Molecular Biology
University of California, Berkeley

Dr. Russell Hulse
1993 Nobel Prize in Physics, Research Physicist and Head, Computer Modeling Group
Princeton Plasma Physics Laboratory

Amy B. Lovins
MacArthur Fellow
Vice President, CFO, Director of Research
Rocky Mountain Institute

Dr. David M. Lee
1996 Nobel Prize in Physics
James Gilbert White Professor, Physical Sciences
Cornell University

Dr. Arthur Kornberg
1959 Nobel Prize in Physiology or Medicine
Professor of Biochemistry
Stanford University

Dr. Eric F. Wieschaus
1995 Nobel Prize in Physiology or Medicine
Squibb Professor of Molecular Biology
Princeton University

Dr. Wallace Broecker
1999 National Medal of Science
Geochemist, Columbia University Lamont-Doherty Earth Observatory

Edward Yourdon
Computer Scientist
Chairman, Cutter Consortium

Dr. Dudley Herschbach
1986 Nobel Prize in Chemistry
Frank B. Baird, Jr. Professor of Science
Harvard University

Dr. Frederick Seitz
1973 National Medal of Science
President Emeritus, Rockefeller University, Past President, National Academy of Sciences

Lt. Col. Pamela A. Melroy
NASA Astronaut
Space Shuttle Pilot

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